



## TALKING POINT:

### PATIENT POWER

- Involves understanding your options to make empowered decisions to get the best care
- One of the greatest barriers to patient participation in clinical trials is a lack of awareness by both patients and their doctors
- Patients now have the power to look for new treatments and trials related to their specific disease
- If you are a patient and think you may benefit from participating in a clinical trial you should raise the topic with your doctor and ask for information about clinical trials
- See page 5 for more information



## Issue 1 June 2018

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## Message from the Director

BCNI, established in 2015, is now approaching its half-way point and there has been fantastic progress in all BCNI activities particularly over the last year or so.

We now have 5 core BCNI sites located in Galway, Cork and Dublin (St James's, Beaumont and the Mater) that are involved in clinical trials and biobanking. We've opened three Phase I clinical trials and will have at least two more opening this year providing patients with access to treatments that would otherwise not be possible. Enhanced blood cancer registration is also forging ahead with successful pilot studies completed in Cork University Hospital and national roll-out for AML and MM commencing this summer. The number of samples collected for the biobank is increasing every day and we are grateful to patients for providing their samples, as well as to colleagues who collect and process the samples. This will be a fantastic resource for research into understanding blood cancers and developing new and personalized treatments.

BCNI has also carried out a lot of work to reach medical staff, researchers, patients and the public, to tell them about our activities and to get them involved wherever possible. We've visited schools and run events that teach kids about blood and clinical trials as well as organising educational lectures for patients and the public on blood cancers and new developments in treatments. The team have also organised and participated in educational events for medical staff to increase awareness of, and participation in our activities. Our annual symposium on Blood Cancer Research is becoming one of the most important national meetings in translational and clinical research on blood cancers. The value of BCNI activities is now being recognised by industry and this is demonstrated by the support they are providing for BCNI activities.

BCNI has made huge strides in the past two and half years and I look forward to further updating you on our progress in the next issue of the newsletter.

**Prof Michael O'Dwyer**

## MEET SOME OF OUR TEAM MEMBERS

Dr Grainne Gannon joined the BCNI team in July 2017 as Clinical Trials Network Manager. Grainne has a PhD in Molecular Biology and more than 10 years' experience in Clinical Trial Project Management and leading clinical study teams at Novartis, ICON and Pfizer.



Jessica Walsh has joined the team at Galway University Hospital as our Research Nurse. Jess's role is to support BCNI early phase hematology clinical trials within the Clinical Research Facility. Jess has a Masters in Research Methods and extensive experience as a research nurse and we are delighted to have her on the team.



## Clinical Trials

BCNI has 5 sites located in Galway University Hospital, Cork University Hospital, St James, Beaumont and the Mater that carry out early stage clinical trials. We have dedicated and experienced research staff at each site to look after patients and ensure that the trials are run according to protocol and good clinical practice. The BCNI research nurses work closely with the Investigators and ensure that patients are given the support and care needed in these early phase trials.

### Our clinical trials

#### **CyBorD DARA**

This innovative Phase 1 clinical trial is investigating whether the addition of a new multiple myeloma treatment, Daratumumab (DARA), to a standard of care chemotherapy containing the drugs Cyclophosphamide and Bortezomib (CyBorD), is beneficial for treating newly diagnosed patients. DARA by itself is a very promising new therapy for this particular cancer and has recently been approved for treating relapsed patients and even newly diagnosed patients not planning to have stem cell transplantation. This new trial is the first study worldwide to combine DARA with Cyclophosphamide to see if this combination results in a more effective treatment. Initial results from this trial are very positive as the combination shows a promising response rate and is well tolerated. Preliminary results were presented at the American Society of Hematology meeting in Dec 2017.

**Recruitment closed in Dec 2017.**

**GMI 1271-230-** BCNI is leading the way in evaluating whether a drug GMI-1271 is effective in patients with multiple myeloma in combination with standard of care chemotherapy. The drug works by preventing the cancer cells from hiding out in the protective environment of the bone marrow, thereby allowing chemotherapy treatment to kill the cancer cells. **Actively recruiting!**

**GMI 1271-201.** This Phase I/II trial is evaluating the combination of GMI 1271 with chemotherapy in patients with AML. Initial results showed that GMI 1271 plus chemotherapy was well tolerated with a high remission rate and these findings were presented at the American Society of Hematology meeting in Dec 2017.

**Now closed to recruitment.**

**GMI 1271 recently received FDA breakthrough therapy designation for adult relapsed refractory AML!!**

### **Opening soon.....**

European Myeloma Network study - newly diagnosed transplant eligible Multiple Myeloma with CyBorD DARA arm (phase II DARA VCd vs. VTd)

GMI-1272-301 Phase III GMI 1271 plus chemo versus chemo alone in relapsed refractory AML.

## SOME OF THE BIOBANKING TEAM

Tatiana Cichocka is a new addition to the team at NUI Galway. Tatiana is involved in coordinating biobanking activities at all of the BCNI sites and she also collects and processes blood and bone marrow samples at the NUI Galway.



Juliet Barry is part of the Biobanking team at UCC/Cork University Hospital. Juliet has been with the team since the launch of BCNI



Sarah Brophy is a new addition to the Biobanking team at TCD/St James's.



## Biobank

BCNI has a Biobank unit called Blood Cancer Biobank Ireland, or BCBI. It collects tissue samples donated by patients who have a blood cancer. It is a national effort with biospecimen collection currently taking place in hospitals in Galway, Dublin and Cork and in the future we hope to collect samples from patients all over Ireland. The collected tissues are processed to obtain materials that are useful for researchers for clinical and biomedical research, such as testing the efficacy and safety of new drugs developed against blood cancers

The BCNI biobank collects and stores blood and bone marrow samples from patients. These samples are used to help researchers understand how blood cancers develop and to help discover new treatments.

BCBI stores:

- Live leukemic cells and live bone marrow stromal cells (for testing the safety and efficacy of drugs)
- RNA and DNA isolated from the leukemic and bone marrow stromal cells (for examining the genetic abnormalities causing the cancer)

Researchers study these samples to understand how blood cancers develop and how we can design better treatments for blood cancer patients. To use biobanked samples, researchers make an application to the biobank where they explain how they plan to use the samples and how it would benefit patients. Over time, the research done on the biobanked samples will become an invaluable asset that will help our understanding of how blood cancers develop and help doctors to determine what is the best treatment for each patient.

### Currently:

- Collecting acute myeloid leukaemia (AML), multiple myeloma (MM) and chronic lymphocytic leukaemia (CLL) samples at Cork University Hospital, Galway University Hospital, St James's, The Mater and Beaumont hospitals.
- All the hospital sites use standardised protocols for collection and isolation of genetic material and cells from the bone marrow and peripheral blood. No additional procedures are necessary for patients. Samples will be taken, with consent, during normal clinical care.
- Storage of the associated patient information for all the samples is on a secure, custom made database.

If you would like to have access to these samples as a **researcher** please contact Dr. Eva Szegezdi (eva.szegezdi@nuigalway.ie) for further information. For more information on the BCNI biobank please see [www.bloodcancers.ie/bloodcancers/bloodcancerbiobank](http://www.bloodcancers.ie/bloodcancers/bloodcancerbiobank)

## REGISTRY TEAM

Rose Mc Morrow is our new Blood Cancer Data Registrar. Rose will collect clinical data on blood cancer patients from hospitals in the Munster Region.



Kieran Cronin is our systems/data analyst for blood cancer registration and is based at the National Cancer Registry in Cork. Kieran has developed databases for the different forms of blood cancers and will be involved in storing and analysing the data that Rose and the other data registrars collect.



## Blood Cancer Registry

**The blood cancer registry aims to collect high quality, detailed clinical data as well as Patient Reported Outcomes Measures (PROMS) on all patients with blood cancers diagnosed in Ireland. This will help us understand which treatments have the best clinical outcomes with the best quality of life for patients.**

**The National Cancer Registry, a partner in BCNI, has been working in close collaboration with haematologists in Cork University Hospital to develop an Enhanced Blood Cancer Outcomes Registry (EBCOR) which will soon be rolled out nationally.**

- Data specifications have been prepared for Acute Myeloid Leukaemia and Multiple Myeloma with work on Chronic Lymphoid Leukaemia and Lymphoma at an advanced stage.
- The database is being reviewed by key users in the National Cancer Control Programme, Cancer Trials Ireland, Epidemiologists and health economists to ensure that the data can be used across a range of functions including outcome monitoring in clinical trials, pharmaco-economic evaluation and in the development and evaluation of services and policy.
- The registry database will be further extended to capture Myeloproliferative Neoplasms, Myelodysplasia Syndromes, Aplastic Anemia and Acute Lymphocytic Leukaemia.

### **Preparations are at an advanced stage to roll out EBCOR across the Munster Region.**

Rose McMorrow the Blood Cancer Registrar has established links with Cork, Limerick and Waterford University hospitals as well as regional and private hospitals in the region. Recruitment of registrars for Galway and Dublin has commenced with the aim to begin registration during the summer and complete registration for AML and Multiple Myeloma for patients diagnosed in 2018 by spring 2019.

A key aspect of cancer registration is finding new cases. The BCNI team at the NCRI have worked closely with the chief clinical scientists in Cork University Hospital to develop a rapid process for case ascertainment. This approach will be tested locally before developing similar methods elsewhere. It has the potential to significantly increase the timeliness and completeness of registration beyond what is currently possible.

The NCRI are currently planning the development of longitudinal patient reported outcomes surveys in blood cancer patients for the first time. Protocols, ethics applications and questionnaires are currently being prepared. Clinical support for this work programme will be sought through the Network in the autumn with the view to begin data collection in early 2019.

## Patient Power!!

Every person is either a patient or a future patient and as we all know our health system is stressed to capacity. It is therefore critical for each of us to learn the basics about our own personal health and about disease prevention and treatment. Patient power essentially means taking ownership of our own health and educating ourselves so that we understand our options, can find the appropriate resources to help us make important decisions and can contribute to improving treatment. Educating ourselves, even just a little, about our own cancer will help us make more capable treatment decisions, and lead to better discussions with our doctor.

Patient power can take a number of different forms, for example:

- People who have been affected by cancer can help shape research and find better treatments by sharing their experiences of diagnosis, treatment and care.
- Patients can provide invaluable insights that will help researchers design and develop their research studies.
- Patients can provide samples for biobanks that help researchers understand cancer and develop new treatments.
- Patients can provide information for cancer registries to help improve cancer outcomes and reduce the cancer burden. BCNI's enhanced blood cancer registry will allow us to understand what treatments patients are receiving nationally, what is working well, and what issues and services are important for patients.
- Patients can participate in clinical trials to evaluate new treatments while receiving excellent care and access to novel drugs that may not otherwise be possible.
- Cancer clinical trials can offer patients tomorrow's best treatment TODAY!

When it comes to **clinical trials** one of the **greatest barriers** to patient participation is a **lack of awareness**. Generally speaking, clinical trials are not spoken about in regular doctor/patient appointments as a treatment option. Ideally they should be part of every post-diagnosis consultation. All patients need to know what type of illness they have and whether there is a current or possible future treatment. So once patients have come to terms with their diagnosis, clinical trial opportunities should factor into any discussion of treatment options.

Nowdays Patients are becoming empowered —there are a growing number of online clinical trial finder tools that can easily be accessed by both medical teams, patients and their carers to search for appropriate trials based on a patient's disease. This means patients now have the power to look for new treatments and trials related to their specific disease that their own doctors may not be aware of.

**If you think you may benefit from participating in a clinical trial you should raise the topic with your doctor and ask for information about clinical trials.**

**If you would like to provide a sample for the biobank or information for the registry please tell your doctor. You will be providing a valuable service for many patients who will be diagnosed after you are. As we all fight blood cancers remember that only YOU can give this extremely valuable tissue!**

## BCNI IN THE NEWS

- Prof Michael O'Dwyer talked to Galway Bay FM about Blood Cancers and explained BCNI's research and clinical activities to increase understanding of blood cancers and to improve treatments for blood cancer patients



- Dr John Quinn and Prof Michael O'Dwyer took part in the "Make Blood Cancer Visible" campaign which aims to raise awareness of blood cancers. The campaign highlighted the signs and symptoms of Blood Cancers and the research being done to develop new treatments.



- Prof Michael O'Dwyer talked to Myeloma Crowd Radio about his research and how sugar molecules can act as a camouflage to help myeloma cells hide from the immune system

- BCNI researchers recently published significant new findings in the journal "Leukemia" providing a rationale for targeting E-selectin receptor/ligand interactions to overcome metastasis and chemoresistance in Multiple Myeloma

## Outreach

Prof Michael O'Dwyer on Morning Ireland with Barry McGuigan as part of the "Make Blood Cancer Visible" campaign



Research nurse Jessica Walsh and clinical trials coordinator Grainne Gannon attended the Irish Cancer Society's annual conference on cancer survivorship and took part in Make Blood Cancer Visible" campaign. The patient events were open to all people, along with their family and friends, who are living with cancer.



Dr Eva Szegezdi's article for RTE brainstorm discusses how the Bone Marrow can act as a protective environment for cancer cells helping them to grow and to hide from chemotherapeutic drugs



A "Blood Cancer Information Evening" was held in November in Galway. This event was open to patients, their families and members of the public with an interest in learning more about blood cancers. We had a great turn out for the event which included patients, their families as well as medical and research staff and students and the venue was full to capacity!



Prof Mary Cahill gave a talk on "Blood Cancer Trials: How we can help current and future patients" at the 2nd Cancer Clinical Trials Educational Workshop at Cork University Hospital. The event was part of International Clinical trials day and was aimed at informing healthcare professionals about clinical trials.



Research nurse Jess and research assistant Shauni took part in START (schools teaching awareness of randomised trials) at NUI Galway where they met with primary school students to talk about BCNI clinical trials





Public/patient  
information event  
at 4.00pm on Friday  
8<sup>th</sup> June at  
Beaumont Hospital,  
Dublin

## Upcoming Events

- Come along to our public lecture on blood cancers and advances in treatments at 4.00pm on 8<sup>th</sup> June at Beaumont hospital. Learn about blood cancers and advances in treatment and hear from Dr Jim Omel, a Myeloma patient, FDA advisor and patient advocate!
- Our annual symposium on blood cancers will take place in Beaumont hospital on Friday 8<sup>th</sup> June from 9am-4pm. This event is open to researchers, clinical and industry staff with an interest in blood cancer research and developing new treatments for blood cancers.
- The Young Cancer Researchers Network “Translational Cancer Research Conference” will take place on 21<sup>st</sup> -22<sup>nd</sup> June at University College Cork- details can be found at [www.ucc.ie/en/ycrn](http://www.ucc.ie/en/ycrn)
- BCNI workshop on “Translational Biobanking for Cancer Research” is in planning stages for Q4 2018, University College Cork

For more information on these and other events please see our website [www.bloodcancers.ie/newsevents/](http://www.bloodcancers.ie/newsevents/) and twitter

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Blood Cancer Network Ireland  
[www.bloodcancers.ie](http://www.bloodcancers.ie)

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